

Exploring transplant opportunities in Hmong culture: a case report

A clinical case is used to explore the ethical complexities of solid organ donation and transplantation within the Hmong community in the United States. Although many cultures can present various ethical issues, the challenges of the Hmong belief system are unique and distinctly complex. Ways for the medical team to integrate with the Hmong value system to attempt to create an environment of transcultural respect and appreciation are described. (*Progress in Transplantation*. 2009;19:188-191)

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Transplantation between a live pediatric donor and a parent recipient is rare, but has occurred with both kidneys and livers. According to the United Network for Organ Sharing (UNOS), between 1988 and 2006, directed living donor transplants involving a minor donor occurred 46 times in the United States.¹ Among these transplants (all kidney), 11 involved a child donating to a parent. The case presented here is distinct because it involves a deceased directed donation from a child to a parent amid a Hmong family living in the United States. We suspect this is a rare occurrence, although the statistics are unknown because UNOS does not record such directed donation data.

Deceased directed donation can occur via 2 methods: (1) a person dies and his or her advanced directive denotes organ donation to a specified (identified) recipient; or (2) the individual's surrogate directs the organ donation to a specific recipient. Both of these methods of directed donation are permitted under UNOS guidelines.² Assessing potential directed donations is a complex process because of logistical issues and ethical concerns. In our case, the culture and values of the

Hmong were explored, and interesting intersections with transplant ethics and bioethics were noted. Historically, the Hmong have been opposed to organ donation, citing religious beliefs. Specifically, they generally oppose organ donation because they believe that bodies missing their organs will lack those organs when reincarnated. In the case that follows, these values are challenged and lead us to offer suggestions for discussing organ donation and transplantation with Hmong families.

Case Report

Some details of this case have been changed in order to protect the privacy of the family involved.

A healthy 17-year-old Hmong boy sustained a fatal gunshot wound in a drive-by shooting. His biological father was a 43-year-old man with chronic kidney disease due to hypertensive nephrosclerosis. He had been on hemodialysis for 5 months, but had never been evaluated for kidney transplantation. He was the father of several children and had been married for more than 20 years.

Upon the child's sudden death, his family became interested in the possibility of a kidney transplant from his deceased son. An urgent evaluation was conducted to determine if the adult-size child would be a suitable donor for his father. The organ was determined to be an appropriate match. The transplant team recognized the ethical problem of the father providing consent for the organ to be directed to himself, thus the strategy of maternal consent was arranged. The father gave up parental decision-making rights, and the child's mother consented for the organ donation of 1 kidney, directed to her husband. She did not permit any other organs to be donated.

The kidney transplant was successful. The child's father was discharged 5 days after the transplant and has made a full recovery. Emotionally, he is content with the donation and transplant experience.

Discussion

This case presents a series of clinical ethics issues that the organ procurement organization (OPO) and transplant team had to address in a time-sensitive manner. The main issues identified are (1) traditional Hmong values interacting with Western medicine; (2) directed donation from a deceased child to a parent; (3) the family consented to donation of only 1 organ, leaving the remaining organs unable to be used by other patients on the transplant waiting list; and (4) urgent transplant evaluation for the father (organ recipient).

Cross-cultural medical treatment requires attention to the patient's values and beliefs.³ The Hmong are an ethnically distinct southeast Asian group whose origins are generally traced to central China during the second millennium, BCE. The first Hmong refugees came to the United States in the spring of 1975. Recent US census figures report a nationwide Hmong population of 169 428.⁴ California is home to more Hmong-Americans than any other state, and they are generally concentrated in the Central Valley, specifically in Fresno, Merced, and Sacramento counties.⁵ Large populations of Hmong are also present in Minnesota and Wisconsin.

Traditionally, the Hmong are an agrarian society that is patrilineal, patrilocal, and patriarchal.⁶ The Hmong believe that illnesses may have natural causes that should be treated with herbs, massage, cupping, or other nonspiritual methods. Illnesses could also have supernatural causes, which are believed to be more serious than illnesses of natural causes. Consequently, each village has at least one shaman (healer) who will intercede with the spiritual world.⁷ Recently, shamans have been found to be the connection between Hmong-American patients and Western medical treatment.⁸

Since their arrival in the United States, members of the Hmong community have endured unique challenges in enabling the doctor-patient relationship

essential to engaging in Western medicine. As an example, in the book *The Spirit Catches You and You Fall Down*,⁹ author Anne Fadiman presents the case of Lia Lee. Lia is a 3-year-old girl with epilepsy. Neurologists argued the cause of her seizures was neuronal misfiring, but the family argued it was Lia's spirit trying to leave her body (qaug dab peg).⁹ The Hmong animist belief is that each part of the human body has a soul and is essential. Operations are considered to have short-term and long-term effects on an individual's soul, and the reincarnated soul may have to carry a defect from its physically altered body into the next life. Furthermore, within the Hmong community, distrust toward surgeons is common.^{6,10-12}

In the United States, residents can register to be organ and tissue donors when they die. A private directed donation initiative called LifeSharers allows registered organ donors to receive preferred status for organ allocation from other LifeSharers members when they die.¹³ In other words, members direct that each of their organs goes to the highest ranking qualified LifeSharers member on the UNOS waiting list. As of March 31, 2009, LifeSharers (www.lifesharers.com) had nearly 12 600 members, 40 of whom are waiting for an organ transplant. Although UNOS does not support the concept of donation status as a method of allocating organs, as stated earlier, UNOS does allow directed donation. In California, if a minor elects to register, the responsibility falls to the parents or legal guardian to make the final decision about donation.¹⁴ Other states such as Washington and Missouri also have similar laws. In our case, the deceased child had not registered as an organ or tissue donor. His mother, as the consenting parent, thus had to reflect on whether organ donation would have conflicted with her child's personal beliefs.

When a minor child is deceased, he or she is no longer considered a patient. This raises the ethical question: is the parent the appropriate agent from whom to obtain informed consent for organ donation when he or she is the intended organ recipient?¹⁵ Should that parent revoke his or her parental decision-making right in an effort to reduce conflict of interest in decision making? Should a court-appointed guardian be instituted to protect the dead? Clearly, it is not appropriate for physicians or surgeons to insert themselves and become the surrogate for organ donation consent. Doing so would create a dual role (fraught with conflict of interest). Moreover, patients who need a transplant have no moral claim against their family or others (dead or alive), for a replacement organ.¹⁶ As was done in our case, we suggest it is an ethical necessity for the intended (parent) recipient in a 2-parent family to relinquish his or her legal decision-making rights and have the other parent function as the consenting party. Conflict of interest is

not eliminated (because of the innate connection between the spouses) but it is reduced. We see no advantage to appointing a nonparent relative as the consenting party (eg, child's aunt, uncle, or grandparent) because this person, too, has a conflict of interest just as the recipient's spouse does. Any relative would, in general, make decisions that promote the life of their family member. Appointment of a guardian (a neutral party with no conflict of interest) by the court would be logistically impossible because of the time constraints of organ procurement and transplantation.

This raises the question, what if the intended (parent) recipient is a single parent? Who would provide consent for the directed donation from a deceased minor child to a parent who has no spouse or legal partner? Ethically, this appears to be uncharted territory. As stated earlier, having a court appoint a guardian would be logistically impossible because of the time constraints of organ procurement and transplantation. Perhaps in these situations, an urgent ethics consultation should be conducted in an attempt to determine the values of the child. A deceased child donating to a parent would most likely be a teenager because of body-size matching, thus a child of this age may have previously expressed his or her values about organ donation, even if the child did not register as an organ donor. Further, because surrogate consent should be based on the values of the deceased, exploring these values seems essential. Again, we argue that a parent has no moral claim on his or her child's organ (live or deceased) for himself or herself. Each OPO should also be well versed in the laws of its jurisdiction to ensure that consent is legally sound.

In our case, the family was confronted with the opportunity to procure multiple organs and tissues from their deceased child; however, their decision was directed donation only to a relative and none for society. The recipient did not explain the reasoning behind the directed donation of only 1 organ. Hmong culture aside, data show that donor families more broadly have fears that vary by ethnicity, especially within minority populations.¹⁷

Precedent exists for parents' permitting the procurement of only specified organs for deceased donation from their child. We identified a case in the literature in which a Jehovah's Witness family allowed their deceased child to be an organ donor; however, they allowed only her liver and kidneys to be donated but not her heart.¹⁸ Although consent for organ donation is often a blanket consent for all organs to be gifted to those in need, such is not always the case. Sometimes the donor specifies in advance of death which organs he or she wishes to donate. Surrogate consent works in the same way. Because organ donation is a voluntary act, neither donors nor their surrogates are required to consent to donating all transplantable organs, and the

donor's choice must be respected. This said, it can still be emotionally difficult for medical professionals to witness potentially transplantable organs not being transplanted.

The child's father had not undergone evaluation (and wait listing) for a transplant before his son's death because he was not eager to begin the waiting process for a deceased donor organ, as he had been told the wait would be "9 or 10 years." Also, he viewed organs coming from a blood relative as having optimal clinical function, compared with organs procured from others. The recipient, his wife, and his nephew jointly initiated discussion about directed donation because they knew the child was going to die. He undertook no discussions with a shaman. Within the family, the decision to proceed with directed donation was unanimous.

The fact that the father was not on the transplant waiting list at the time of his child's death created the need for his candidacy to be assessed quickly. Urgent evaluations are difficult to carry out because of the many parties involved and the short time frame, but these evaluations are essential in order to ensure that each patient eventually listed for transplant has the capacity to benefit from transplant. In our case, the evaluations included assessment by a nephrologist, a surgeon, and a social worker. Fortunately, the recipient was young and without significant cardiac disease, which simplified the clinical workup. Overall, the combination of the ethical complexity of a pediatric directed donation to an individual not currently listed for transplantation in the setting of complex cultural values made for a very complex case.

Guidance

The interplay of distinct cultures and Western medical practice can be ethically complex. In our case, open communication between the OPO and the family amidst a tragedy allowed a successful kidney donation to occur. When evaluating a deceased directed pediatric donation, the situation must be analyzed carefully to ensure that the donation is occurring within UNOS guidelines.²

Cultural barriers are ever present in the area of advanced medicine. Organ transplantation is no exception, and further dissemination of knowledge of best practices is needed to help the fund of knowledge for individuals everywhere.¹⁹ Implementation of a special liaison for OPOs that have a significant population of Hmong families could be of benefit. The Hmong liaison would establish a relationship with the Hmong community and local shamans. This relationship building is of particular need in areas of the United States where the Hmong-American population is large. Liaisons of this nature are helpful in general clinical settings.²⁰ Similarly, transplant coordinators with competence in a specific cultural demographic also are beneficial.^{21,22}

Transplantation is time sensitive, thus quick resolution of ethical dilemmas is essential. In challenging cases like this, OPOs (and all those involved) should have access to ethics consultation services.²³ Although hospitals can turn to their ethics committee or ethicist, OPOs often do not have their own ethicist on staff. We advise that they retain the services of an ethics consultant with expertise in transplant ethics on an on-call basis. The advice received from these consultations is advisory only and is not binding. Hospitals and OPOs retain the option of accepting, rejecting, or modifying the consultant's recommendations. Further, ethics advice is not the same as legal advice. Legal advice should be obtained only from a qualified attorney.

Sometimes, cultural values are deeply interwoven into family life and values, making them difficult to express because, to the family, they are innate to their thought processing and decision making. Great lessons can be learned from exploring organ donation, transplant, and Hmong traditions.²⁴ Having a general understanding of diverse cultures can benefit transplant teams in their daily work with patients from all walks of life. Further, we speculate that lessons learned from one culture could potentially help in the exploration and framing of donation and transplant discussions with patients and families of other non-Western cultures.

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